PELC
Partnership of East London Co-operatives Ltd

HM Coroner's Office
HM Senior Coroner Graeme Irvine

Dear Mr Irvine

Regulation 28 Report- Inquest Touching the Death of Miss Urielle Mayila Kuyenga

I write further to your Regulation 28 Report to Prevent Future Deaths (PFDR) dated 09.12.25, relating to the Inquest of Miss Urielle Mayila Kuyenga ('Urielle').

We have considered your concerns and set out our formal response to each matter using your numbering as follows.

Matters of Concern

1. **As a patient with Sickle Cell Disease, Urielle was prescribed prophylactic penicillin to mitigate the risk of her developing fatal symptoms arising from typical respiratory infections. Urielle's mother chose not to collect those prescriptions and administer penicillin to Urielle. Urielle's specialist doctors believed that her GP was monitoring the prescription and dispensation of the penicillin, whilst Urielle's GP was misled by Urielle's mother that the hospital were dispensing the medication directly. The breakdown of communication means that Urielle was left unprotected from opportunist infection which caused this avoidable death.**

2. **In the weeks prior to her death Urielle's mother presented her daughter to three separate GPs about a respiratory infection. On each of these three attendances the attending clinician was ignorant of Urielle's Sickle Cell diagnosis. The reasons for these lapses were, firstly Urielle's mother did not inform the doctor of the fact and, second, that the doctors did not adequately read the clinical records available to them.**

From the outset I would like to reassure you that we have reflected seriously upon the findings at Inquest and upon the contents of your Report, and that we welcome the opportunity to identify learnings, as well as the opportunity to both improve the quality of our care provision and strengthen the existing policies and procedures where appropriate.

I understand that your concerns regarding paragraph 1 have been addressed to other bodies, and I therefore address paragraph 2 as follows.

Response

In our letter dated 30 October 2025, we confirmed the various locations in which a patient's records may be located. We also confirmed that since this tragic incident we had introduced a new requirement that clinicians, when reviewing a child or vulnerable adult, conduct a review of the individual's records.

I can confirm that since then, we have conducted a further review of PELC's policy and have expanded this policy to all patients.

In addition to the above, attached to this letter is a copy of our updated action plan setting out the steps we have taken and will take to ensure that Urielle's experience is not repeated. These include the following:

1. Learning Communication to Staff- Organisational learning has been shared regarding the importance of reviewing all relevant previous patient encounters as part of review of the patient. This learning will continue to be shared at regular intervals so as to ensure that new starters are aware and current employees are reminded.

2. Inclusion in Clinical Staff Contracts- In our letter of 30 October 2025, we confirmed that there was an expectation of clinicians to act within GMC Professional Standards and Good Practice which requires that clinicians must 'adequately assess' the patient. We have now included the requirement to all relevant prior patient encounters a part of staff contracts.

3. Clinical System Alert for Discharge Decisions- We are currently working with Adastra to implement an alert within clinical records for all children presenting to the service with a diagnosis of sickle cell disease.

    a. This alert shall be generared once a patient discloses that they have sickle cell disease or upon identification by a clinician following review of the patient's summary care records. The latter will require patient consent.

Thank you again for bringing your concerns to my attention. I trust that this response provides assurance that appropriate action is being taken to address those concerns.

If you have any further concerns or you would like to discuss this case further, please do not hesitate to contact me.

Yours Sincerely

[redacted]
[redacted] Head of Governance, Nursing & AHPs